The maternity care experiences and needs of migrant women with female genital mutilation living in Australia

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A Dissertation Submitted for the Degree of Doctor of Philosophy

Faculty of Health

University of Technology Sydney (UTS)

February 2020

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Certificate of Original Authorship

I declare that this thesis is submitted in fulfilment of the requirements for the award of doctoral degree, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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Dedication

This work is dedicated to my late mother, ‘Parvin’ who wished to see me at the top of the mountain of success. The woman who sacrificed her dreams for my growth and empowerment. She made me to be the person I am today and constantly motivated me to keep working toward creating the best version of myself.

My mother strongly fought with her whole tribe, traditions and culture to ensure I’d have all the potential opportunities and possibilities to be educated and empowered and achieve my dreams and goals. She taught me to be prepared and to stay strong in the face of challenges and difficulties with faith, resilience and humility. Her life is a constant source of inspiration for me.

Acknowledgments

I am proud of myself for arriving at this day and accomplishing such an important milestone despite all the lumps and bumps in my life. All those challenges and difficulties that I have been through, pushed me toward this point of my life, as an Afghan woman attaining a higher level of education. Coming from a conservative society, where women have no basic human rights, I am honoured and humbled to be the first midwife and one of the few women from Afghanistan who hold a post-graduate research degree. The choice I made to obtain a PhD is not something to be taken for granted, there are millions of women in Afghanistan who continue to face barriers accessing basic levels of education. I am immensely grateful and uphold this honour on behalf of all Afghan women and I now have the confidence, capacity and commitment to do great things and make the situation better for those minorities.

During this journey, many people crossed my path - each inspired me with unique energy and support and each with a new lesson for me to learn. Often times I wish I was able to invite all these people into one room and present my deep gratitude to each of them individually, for their genuine support and kindness. Thank you all for your kindness and support even if I cannot count you all or remember to mention you here, I hope you all feel my love and gratitude.

I would like to acknowledge the boundless support provided by my supervisors Professor Angela Dawson and Distinguished Professor Caroline Homer. Angela, who is truly the most action-oriented person I have ever met. She is wonderful at turning plans into realities and she has been an inspiration to me, helping me to realise how I could turn my research into practical interventions for vulnerable and marginalised women. I developed

enormous respect for Angela's dedication to her profession as an exceptional scientist and public health leader and it was a great blessing to work under her guidance.

Caroline Homer, words are not enough to express my gratitude for her generous support. She supported me in different ways; not only professionally, but also personally and emotionally. She provided me with opportunities that enabled me to survive and thrive. By encouraging and recognising my abilities, Caroline empowered me to recognise that there are limitless possibilities. She has given me the confidence to build up and use my skills and knowledge as woman, midwife and academic for the betterment of others.

Dear Caroline and Angela, I believe the effort you both have put in to build my capacity will have an impact way beyond the Australian borders. You have made this journey a joyful and fruitful experience for me, I feel blessed. Thanks for your love and support.

Deep in my heart, my family means the most, I love them and I am thankful for their loyalty and support. I deeply appreciate my father who is still facing the risks, difficulties and pressure from a patriarchal society because of breaking the norms by providing me with the opportunities to be free and empowered. I am thankful to my siblings who provided me so much emotional support and enabled me to achieve my dreams even in the face of oppression.

I am greatly indebted to many people in the theoretical part of my thesis. I am extremely thankful for all the support provided by Professors Nicky Leap and Pat Brodie for their ideas and insightful recommendations. Nicky and Pat your support was indispensable to the formation of my writing. Thanks so much.

I would like to acknowledge and thank the women who shared their stories. I appreciate them for their honesty and for taking the time to help me achieve a greater understanding of the needs and experiences of women accessing maternity services. I hope I have done

your accounts justice and that other women affected with FGM, may experience a greater quality of care accessing maternity services. Specifically, I thank Awadea, the woman who helped make this study possible by connecting me to the community and making sure I had access to all the resources I needed to conduct this study at ground level.

I am also thankful to my midwifery colleagues at UTS: Dr Christine Catling, Dr Allison Cummins, Dr Deborah Fox, Vanessa Scarf, Nicki Watts, Georgia Brown, who supported me like a family member throughout the good and bad times.

I am thankful to my amazing friends who walked with me during this journey, Laura Moony, Farzad Tofigh, Kate Watson, Nesrin Varol, Libby and Ross Hindmarch, Bev and Michael Horsburgh. Thank you for your thoughts, advice and being there whenever I needed a friend. The connection we have made through this friendship has enriched my life and I am so grateful for your presence in my life.

Thanks to my fellow PhD students and friends, each of whom had a story of encouragement that contributed to my success. Their company made this endeavour easier and fun.

‘Embrace the struggles and let them make you stronger’

Dissemination

Peer reviewed publications

Turkmani, S., Homer, C.S.E. & Dawson, A. 2018, 'Maternity care experiences and health needs of migrant women from female genital mutilation–practicing countries in high-income contexts: A systematic review and meta-synthesis', *Birth*. 46 (1), pp.3 –14

This peer reviewed paper is included in Chapter Two of my thesis and was published during my PhD candidature. Below is the summary of contribution for each author.

Area of contribution	**Percentage of contribution**
Concept and design of the study	ST 90%, AD; CH 10%
Supervision and conduct of research	ST 80%, AD; CH 20%
Data analysis and interpretation	ST 75%, AD; CH 15%
Writing of the initial manuscript	ST 80%, AD;CH 20%
Manuscript revisions	ST 90%, AD; CH 10%

Technical publications

These background papers were also published during my PhD candidature, but they are not part of my thesis.

Turkmani, S., Homer, C., Varol, N. & Dawson, A. 2018, 'A survey of Australian midwives' knowledge, experience, and training needs in relation to female genital mutilation', *Women and Birth*, vol. 31, pp. 25-30.

Varol, N., Hall, J.J., Black, K., **Turkmani, S.** & Dawson, A. 2017, 'Evidence-based policy responses to strengthen health, community and legislative systems that care for women in Australia with female genital mutilation/ cutting', *Reproductive Health*, vol. 14, no. 1, p. 63.

Conference Presentations

1. Turkmani, S., Homer, C., Dawson, A. (2019) Hearing women's voices: a study of the maternity care experiences and needs of migrant and refugee women with female genital mutilation, *Women Deliver Conference,* June 3-6*,* Vancouver, Canada.

2. Turkmani, S., Homer, C., Dawson, A. (2019) The Maternity Care Experience of Women with FGM in Australia. *3rd International Expert meeting on Management and prevention of Female Genital Mutilation/Cutting* May 20-21, Brussels, Belgium.

3. Turkmani, S., Homer, C., Varol, N. & Dawson, A. A survey of Australian midwives' knowledge, experience, and training needs in relation to female genital mutilation. *The Australian College of Midwives 20th National Conference*, November 2017. Adelaide, Australia.

4. Turkmani, S., Homer, C., Dawson, A., Midwives' experience, knowledge and needs regarding the care of women with Female Genital Mutilation in Australia. *31st ICM Triennial Congress,* June 2017, Toronto, Canada.

Funding and grant acknowledgement

I would like to acknowledge and express my deepest gratitude for the financial support from:

Australian Government Research Training Program Scholarship (APA/RTPS)

Centre for Midwifery, Child and Family Heath, UTS

Faculty of Health, UTS Seed Funding

Faculty of Health, UTS Research Student Development Award

Thesis Completion Equity Grant, UTS

UTS Vice-Chancellor's Postgraduate Research Student Conference Fund

Abbreviations

ABS	Australian Bureau of Statistics
AI	Appreciative Inquiry
AIHW	Australian Institute of Health and Welfare
FGDs	Focus Group Discussions
FGM	Female Genital Mutilation
HICs	High Income Countries
HREC	Health Research Ethics Committee
NGOs	Non- Governmental Organisations
NSW	New South Wales
PTSD	Post Traumatic Stress Distress/Disorder
QMNC	Quality Maternal and Newborn Care
RA	Research Assistant
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Child Fund
US	United States
UTS	University of Technology Sydney
WHO	World Health Organization

Glossary of terms

Female Genital Mutilation (FGM): Female genital mutilation (FGM) includes all procedures that involve the partial or total removal of the external genitalia or other injuries to the female genital organs (such as stitching of the labia majora or pricking of the clitoris) for non-medical reasons. World Health Organization (2016a) classified FGM in four types (I, II, III, VI) and, based on its severity, each type has its own sub-classification as explained here:

Type I (Clitoridectomy): Partial or total removal of the clitoris and/or the prepuce. **Type Ia:** removal of the prepuce/clitoral hood and **Type Ib:** removal of the clitoris with the prepuce.

Type II (Excision): Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora. **Type IIa:** removal of the labia minora only, **Type IIb:** partial or total removal of the clitoris and the labia minora and **Type IIc:** partial or total removal of the clitoris, the labia minora and the labia majora.

Type III (Infibulation): Narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris. **Type IIIa:** removal and appositioning the labia minora with or without excision of the clitoris and **Type IIIb:** removal and appositioning the labia majora with or without excision of the clitoris.

Type IV: All other harmful procedures to the female genitalia such as pricking, pulling, piercing, incising, scraping and cauterization for non-medical purposes.

Infibulation: It is the equivalent term for Type III that is explained above.

Re-infibulation: The procedure of sewing to narrow the vaginal opening in a woman after she has been deinfibulated (i.e. after childbirth); also known as re-suturing.

De-infibulation: The practice of cutting open the narrowed vaginal opening in a woman who has been infibulated, which is often necessary for improving health and well-being as well as to allow intercourse or to avoid complications or facilitate childbirth.

FGM-equivalent terms used by women: 'Khetan', 'Sunnat', 'Ferawni', 'Guduttan', 'Cut', 'Closed', 'Circumcised', 'Excised'.

Abstract

Background

Female genital mutilation (FGM) is a cultural practice defined as the partial or total removal of the external female genitalia for non-therapeutic reasons. Changing patterns of migration have resulted in clinicians in high-income countries caring for more women from countries where FGM is traditionally practised. Women affected by FGM who are pregnant and giving birth may require specialist care depending on their individual needs and type of FGM. However, many clinicians in these countries are unfamiliar with FGM, posing a challenge to the provision of quality of care. There is a lack of research in high-income countries that focuses on the maternity care experiences of women with FGM, that is necessary to ensure quality care.

Aim

The aim of this study was to explore the maternity care experience and needs of women affected by FGM who have migrated to Australia and to inform culturally safe and high-quality woman-centred care and contribute to maternity policy and practice improvements.

Method

Appreciative Inquiry was used as a collaborative approach to identify positive care experiences and create a participatory approach to engage women. Women with FGM were recruited through chain referral and the involvement of a community. Twenty-three semi-structured interviews and four focus group discussions (FGDs) were conducted in metropolitan Sydney. All data, including field notes, were analysed thematically using the 4Ds cycle of Appreciative Inquiry (Discovery, Dream, Design and Develop).

Results

Twenty-seven women affected by FGM from a range of countries participated in this study. The analysis revealed five major themes: (1) My FGM story, (2) appreciating the best in their experiences; (3) achieving their own dreams; (4) planning together; and (5) acting, modifying, improving and sustaining.

Subjective measures of ideal quality maternity care were identified based on women's perceptions and expectations. Women acknowledged the reality of maternity care and situations when it was not of the quality they desired or expected. Women reported that they were not always engaged in all aspects of their care. Most women expressed their desire to play an active role in their care, but they struggled with poor communication and a lack of information tailored to their individual needs. Women identified their meaningful involvement in the design and delivery of their care as a key strategy for improving and validating the quality of the maternity services they received.

Discussion

Women with FGM in this study had a clear understanding of their health and cultural needs. It is necessary to engage women as equals in the design and delivery of their own health care services. Such a level of partnership will ensure and sustain the quality of health services by centring woman and collaborating with them to deliver health care that meets their physical, emotional and cultural needs, thereby achieving quality care for affected women.

Conclusion

This study is one of the first of its kind in Australia and provides an understanding of policy, socio-cultural and healthcare gaps, and strategies required to build self-efficacy

and improve health outcomes for women with FGM. The findings from this research can be used as an advocacy tool or guideline to inform policy and practice and improve the quality of care for affected women through a participatory approach to co-designing future maternity care for women affected by FGM.